STATE OF CONNECTICUT

DEPARTMENT OF PUBLIC HEALTH

TESTIMONY PRESENTED BEFORE THE COMMITTEE ON PUBLIC HEALTH
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House Bill 6263, An Act Requiring the Administration of a Screening Test for Cystic Fibrosis to Newborn Infants

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The Department of Public Health provides the following information regarding HB 6263.

This legislation would require the administrators of Connecticut's birthing hospitals to ensure that all newborns in their care are screened for Cystic Fibrosis (CF). The U.S. Secretary of Health and Human Services has endorsed a listing of disorders to serve as guidance for all state newborn screening (NBS) programs. Connecticut currently mandates testing for all of the Secretary's recommended disorders except CF. We are the only state in the nation that does not require CF testing.

Department of Public Health Newborn Screening Program:

- NBS is a population-based public health program.
- Sound public policy dictates that NBS not be outsourced and fragmented, and that DPH carry out all mandated screening consistent with its current statutory responsibility for over 40 disorders.
- DPH's program is a coordinated, integrated system of testing, tracking, diagnosis/treatment, and program evaluation.
- DPH is best positioned to deliver comprehensive, timely, and effective services.
- Each process within DPH's well-proven system adds value, contributing to an extraordinary level of quality assurance serving the best interests of our newborns.

CF is an inherited disorder that occurs in all races, with an incidence of one in every 3,500 live births. More than 10 million Americans are gene carriers for CF. Approximately 1,000 new cases are diagnosed each year. Although CF is an inborn disorder, symptoms may not appear immediately. Most individuals are diagnosed by age three, but nearly eight percent of cases are aged 18 or older at diagnosis. CF causes impaired respiratory and digestive functions, including severe malnutrition. Early identification of CF and prompt initiation of medical management improves growth and reduces infections. This in turn increases lifespan. Evidence is mounting that NBS does improve quality and length of life.

In Connecticut, Yale-New Haven Hospital and the University of Connecticut Health Center (UCHC) currently test for CF on a voluntary basis, using different protocols. Yale tests approximately 6,000 babies annually with a positive screening rate of 5.0%; UCHC tests approximately 24,000 babies with a positive screening rate of 4.0%. This bill would make CF testing mandatory for the 44,000 babies born here each year.

Thank you for your consideration of the Department's testimony on House Bill 6263.

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